



Mission Statement

INCLUDE HERE THE MISSION FOR THE GROUP.

The goal of the neurocognitive outcomes working group is to identify standardized and specific cognitive assessment tools for use as endpoints in NF clinical trials. Our group critically reviews existing standardized cognitive assessment tools and provides recommendations for a core test bank of neurocognitive measures across cognitive domains to be utilized in NF1 clinical trials. We assess both performance-based tests and behavioral rating scales. Our group also functions as a resource for researchers in the development of cognitive protocols.

Group Focus Areas:

The group is assessing measures in the core domains of attention, executive function, social skills, and behavioral/emotional functioning using a systematic review and rating method developed by the PRO working group. Our group is available to consult with researchers who are considering using cognitive measures as NF clinical trial endpoints. A subcommittee is focused on preschool assessment measures.

Current Members

** denotes member of preschool committee*

Researchers & Clinicians (Institution/email)
Jennifer Janusz, PsyD (Chair)- Children's Hospital Colorado- Jennifer.janusz@childrenscolorado.org *
Cynthia Campen, MD, MS- Stanford Children's Hospital
Pete de Blank, MD- Cincinnati Children's Hospital *
Allison del Castillo- Children's National Health System *
Deborah Gold, MD- UH Rainbow Babies and Children's Hospital
Kristina Haebich, DPsych- Murdoch Children's Research Institute
Kristi Hardy, PhD- Children's National Health System
Matt Hocking, PhD- Children's Hospital of Philadelphia
Kelly Janke, PhD- Children's Hospital of Philadelphia *
Bonnie Klein-Tasman, PhD- University of Wisconsin- Milwaukee (Chair, Preschool Subcommittee) *
Kristin Lee- University of Wisconsin-Milwaukee *
Staci Martin, PhD- National Cancer Institute
Stephanie Morris, MD- Washington University School of Medicine St. Louis
Sara Pardej- University of Wisconsin- Milwaukee *
Jonathan Payne, DPsych- Murdoch Children's Research Institute *
Tena Rosser, MD- Children's Hospital Los Angeles
Pete Stavinoha, PhD- University of Texas MD Anderson
Heather Thompson, PhD, CCC-SLP- California State University, Sacramento *
Karin Walsh, PsyD- Children's National Health System *
Nicole Ullrich, MD, PhD- Boston Children's Hospital



Joanna Wallace, PhD- Stanford Children's Hospital
Pam Wolters, PhD- National Cancer Institute
Patient Representatives
Dena Hasselberg
Maureen Hussey
Connie Sorman
Melissa White
Tracy Wirtanen

Endpoints Published (.pdf reference):

- A. Walsh KS, Janusz J, Wolters PL, Martin S, Klein-Tasman BP, Toledo-Tamula MA, Thompson HL, Payne JM, Hardy KK, de Blank P, Semerjian C, Gray LS, Solomon SE, Ullrich N, the REINS International Collaboration. Neurocognitive outcomes in neurofibromatosis clinical trials: recommendations for the domain of attention. *Neurology*. 2016;87(Suppl 1):S21-S30.

Endpoints Being Evaluated (Project lead):

- A. Measures of social skills (Jennifer Janusz, PsyD)
- B. Preschool measures of attention (Bonnie Klein-Tasman, PhD)

Next Major Milestone (Project Lead, Target Date)

Our group will disseminate final recommendations for social skills measures in the next REINS supplement (target date: December 2019).

Meeting Schedule (Coordinator's contact info):

Neurocognitive committee meets monthly on a rotating schedule. Contact Jennifer Janusz for specific dates (jennifer.janusz@childrenscolorado.org)

Preschool subcommittee meets monthly. Contact Bonnie Klein-Tasman for specific dates (bklein@uwm.edu)